So talk of autonomy or workload does not answer the question of what genetic counselling is aiming to achieve, or what counts as success. These questions need to be answered if patients are to be better informed about the service they are being provided with, as advocated by Chadwick.

Clarke tries to deal with the problem by broadening the remit of genetic counselling beyond information relevant to reproductive choice to diagnosis and support for those with genetic disease, and by broadening the measure of effectiveness beyond workload to include patient and referrer satisfaction. Both are steps in the right direction, but they are not sufficient. First, I will deal with the process of counselling; second, with the outcome, and third with the input.

Effective counselling requires effective communication: giving information that is relevant to patients' concerns in a way that is easily understood. We know something about what issues genetic counsellors address, but less about whether these are the issues of most concern to patients (3). We have little information about the extent to which patients' views are elicited or the extent to which counselling style is 'non-directive'.

In terms of outcome, we know something about what patients recall of what they have been told, but less about what they understand and value of what they have been told (4). We know little about the extent to which counsellors have accurately judged patient concerns or met their needs.

Neither patient nor counsellor comes to the consultation as a blank sheet. Each brings their experience, expectations and beliefs. These will shape the process of the consultation and may be important in understanding the outcome and how it is achieved.

In conclusion, there appears to be a lack of clarity about what counts as success *in principle*. Despite this, we can make progress in answering the question of what counts as success *in practice*. The empirical study of the processes of counselling, and how they relate to a variety of outcome measures, can inform us as to what the *active* ingredients of counselling are. Once this is known, the discussion of which of the active ingredients count as *effective* will be easier.

Any discussion of effectiveness, evaluation or success inevitably raises the question of objectives, which include value systems. The discussion between Chadwick and Clarke is useful in helping to make this explicit amongst health professionals, as a first step to enabling it to be made explicit to patients. The debate about 'what counts as success in genetic counselling?' would be strengthened by:

- more evidence about the input to, the processes and outcomes of counselling, and the relationships between them, and
- the inclusion of purchasers and users of the service.

References

(1) Chadwick R F. What counts as success in genetic counselling? *Journal of medical ethics* 1993; 19: 43–46.
(2) Clarke A. Response to: What counts as success in genetic counselling? *Journal of medical ethics* 1993; 19: 47–49.
(3) Sorenson J, Swazey J, Scotch N. Reproductive pasts, reproductive futures: genetic counselling and its effectiveness. *Birth defects* [original article series] 1981; 17: 4. New York: Alan R Liss, 1981.
(4) Tuckett D A, Boulton M, Olson C. A new approach to the measurement of patients' understanding of what they are told in medical consultations. *Journal of health and social behaviour* 1985; 26: 27–38.

SUSAN MICHIE Dphil, CPsychol
Research Fellow in Health Psychology, Guy's and St Thomas's Medical and Dental School, Ground Floor, Old Medical School Building, Guy's Campus, London SE1 9RT

The ethics of paid versus volunteer blood donation

SIR

I read with interest the recent article by Pablo Rodriguez del Pozo concerning the ethics of payment to blood donors (1). This issue has been debated for decades, not so much from an ethical viewpoint, unfortunately, but usually in connection with disease transmission, economic factors, and/or emotional and political factors (2). Prior to the switch to an all-volunteer blood supply in the United States in the 1970s, ethical concerns were not a prominent part of the debate to eliminate paid blood donors (2,3). That debate centred on a perceived higher incidence of post-transfusion hepatitis from donors paid for their blood donation. However, the debate was also fuelled by misinterpretation of the available scientific data, political manoeuvring by organizations involved in the collection and sale of blood in the United States, and public hysteria and misperceptions of the issues (2,3). Ethical discussion relative to the monetary payment of blood donors is long overdue.

I agree with del Pozo that an all-volunteer blood donation system is imperfect and room could, perhaps should, be made to allow for paid donation. Allowing paid blood donation in certain well defined circumstances is just now being scientifically restudied in light of better donor-screening methods, education, and infectious-disease testing, and the results are encouraging (4,5). As del Pozo points out, even in an all-volunteer donor system, someone still has to pay for the blood. In the United States, it is not uncommon for blood donors to secure non-monetary benefits for blood donation such as, time off from work, free meals, recognition banquets, and various other free gifts. With increased budgetary constraints facing corporations and businesses many employers will be carefully evaluating the impact of such indirect costs when an employee takes time off work to donate blood. Is it fair to make others (for example, employers) indirectly pay for such a 'volunteer' donation? Would it not be reasonable, at least in certain circumstances, to cultivate a cadre of paid donors? Does monetary payment necessarily negate altruism? Is it fair and equitable continually to ask individuals altruistically and freely to donate their red blood cells, their platelets and their plasma when there are profits generated from the sale of those blood components which are not realized by the donor? In addition, it is time, and appropriate, that the various non-monetary incentives and mechanisms used to recruit and compensate blood donors also underwent ethical scrutiny as part of this debate (5,6).

Currently, one rationalization for those few pockets of paid blood donation activity in the United States is the necessity to prevent shortages. However, shortages continue to occur in many, and sometimes most, parts of the country several times a year.

Perhaps, as del Pozo points out, we should be inspired to ethically evaluate and debate paid blood donation, if only as part of an attempt to prevent shortages of blood occurring.

Up until the present, ethical discussion has generally been lacking on many issues confronting blood banking and transfusion medicine. This is no less important at a time when the majority of the world is promoting and holding up the non-remunerated donor as the only safe blood donor (7). The article by del Pozo will serve as a point of departure for the many ethical debates that are yet to come, and should come, in this and related areas in transfusion medicine.

References

(1) del Pozo P R. Paying donors and the ethics of blood supply. *Journal of medical ethics* 1994; 20: 31–35.
(2) Domen R E. Paid versus volunteer blood donation: a historical review [submitted for publication].
(3) Schmidt P J. National blood policy, 1977: a study in the politics of health. *Progressive hematology* 1977; 10: 151–172.
(4) Strauss R G, Ludwig G A, Smith W V, *et al.* Concurrent comparison of the safety of paid cytapheresis and volunteer whole-blood donors. *Transfusion* 1994; 34: 116–121.
(5) Huestis D W, Taswell H F. Donors and dollars. *Transfusion* 1994; 34: 96–97.
(6) Read E J, Herron R M, Hughes D M. Effect of non-monetary incentives on safety of blood donations [abstract]. *Transfusion* 1993; 33 [suppl]: 45S.
(7) Consensus statement on how to achieve a safe and adequate blood supply by recruitment and retention of voluntary, non-remunerated blood donors. *Transfusion today* 1994; 18: 1–2.

RONALD E DOMEN, MD,
Section of Blood Banking and Transfusion Medicine, L-20
The Cleveland Clinic Foundation,
9500 Euclid Avenue,
Cleveland, Ohio 44195,
USA

Drug trial ethics

SIR

I would be grateful for the views of your readers about the ethics of open-continuation studies after the double-blind, placebo-controlled phase of a drug trial. The ethical committee at my hospital take the view that continuation studies are never justified because they give little scientific information and any humanitarian benefit is out-weighed by the danger of giving a drug with unknown efficacy.

I have always taken the view that ethical decisions are rarely absolute but depend on balancing relative values. Even taking a life may be justified if by so doing one saves more lives (when, for example, a terrorist is about to blow up an aircraft). I would suggest that the same principle applies to continuation studies. If the treatment under study is for a self-limited condition like eczema, where there are recognised and effective remedies available, it would seem incontrovertible that a continuation study before analysis of the outcome of the double-blind phase was of doubtful value. If, however, the disease is progressive, ultimately lethal, treatments are more likely to be effective in the early phase, and there are no known effective remedies available, I would suggest that giving all participants of the double-blind phase a chance to try the 'active' medication was essential, and to deny them this opportunity was itself unethical.

Clearly another factor to weigh in the balance is the risk of side-effects, a drug with serious side-effects requiring more evidence of efficacy than one without.

The issue has arisen over a proposal to allow subjects with Alzheimer's disease who have completed a 12-week double-blind phase to go on ondansetron in a dose far below that given for nausea and for which the risk of side-effects must be very small.

One agrees that this phase is essentially for humanitarian reasons although it would allow one to examine the important issue of whether the drug slows the progression of the disease, in which case those on the double-blind active wing would always remain ahead of those starting later, or whether it only causes a functional improvement, the later starters catching up with the others.

The statistical power of a study is increased by delaying the analysis until data collection is complete but the time this takes makes it likely that the first participants in the study would have deteriorated too far to benefit when the final results were through.

My patients and their relatives are alarmed at the prospect that they may be prevented from trying this treatment through an ethical decision which to my biased mind is decidedly unethical.

DR J M KELLETT
Division of Geriatric Medicine,
St George's Hospital Medical School,
University of London,
Level 01,
Jenner Wing,
Cranmer Terrace,
London SW17 0RE

In defence of ageism

SIR

Dr Shaw's article (1) contains flawed arguments and contradictions. One of his principal contentions is that as age is objective it should be used a criterion for rationing as to do so negates the necessity for making subjective value judgements. Dr Shaw writes: 'age is an objective factor in rationing decisions', implying that it is right that it should be. He further writes: 'Health care should be preferentially allocated to younger patients'. However, later in his article Dr Shaw writes, referring to the Bradford Coronary Care Unit Model which he says should be copied, 'The care is targeted on younger patients but none are denied treatment where need arises and benefit is substantial.' This seems to me to show that Dr Shaw does not believe in ageism. If he did, he would not advocate the treatment of *any* elderly patients once they had reached the cut-off age that had been decided on. Surely the whole point of an ageist policy was that after a certain age had been reached the patient would not receive treatment whatever the benefit. (Note that Dr Shaw refers to treatment, as opposed to care, as he makes the point that treatment is given if the ensuing 'benefit would be substantial'. This is an important point because Dr Shaw cannot claim that all he is suggesting is that patients of all ages should be given care, which is different from saying all patients should be given treatment.)

Dr Shaw makes other assertions that should not be accepted on face value. He assumes that the elderly would willingly give up their lives in favour of the young. He gives the example of the grandmother who would want the lifebelt to be thrown to her granddaughter before herself.